

Becoming a professional cancer patient advocate

A new niche market practice for primary care physicians

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John, a 50-year-old attorney, sees his primary care physician because of shortness of breath, easy bruising, and nosebleeds. Clinical and laboratory investigations show that he has multiple myeloma. His primary care physician offers to be John's cancer patient advocate.

The physician, specially trained as a professional cancer patient advocate, helps John with gathering the names of experts on multiple myeloma and arranging appointments with them. John solicits three opinions and then discusses with his primary care practitioner and patient advocate the treatment protocols offered by the three specialists. On the basis of John's personal and family values, as well as medical evidence on the efficacy of these different protocols, John and his primary care physician schedule "Advocate sessions" as part of his physician's new niche market fee-for-service practice offerings. These sessions are dedicated to listening to John's needs and helping him to make critical and difficult decisions.

As a cancer patient advocate, John's primary care physician helps him make home and family arrangements. John wants to be near his wife, children, and friends, so he chooses a local treatment center rather than seeking care from

the national expert who is 500 miles away. John wants help in telling his children, friends, and extended family about his diagnosis of cancer, and so his primary care physician refers him to a psychologist. Using the resource and templates book he has developed, his physician also helps him understand and manage a complex list of medications and a vast array of appointments with different health professionals.

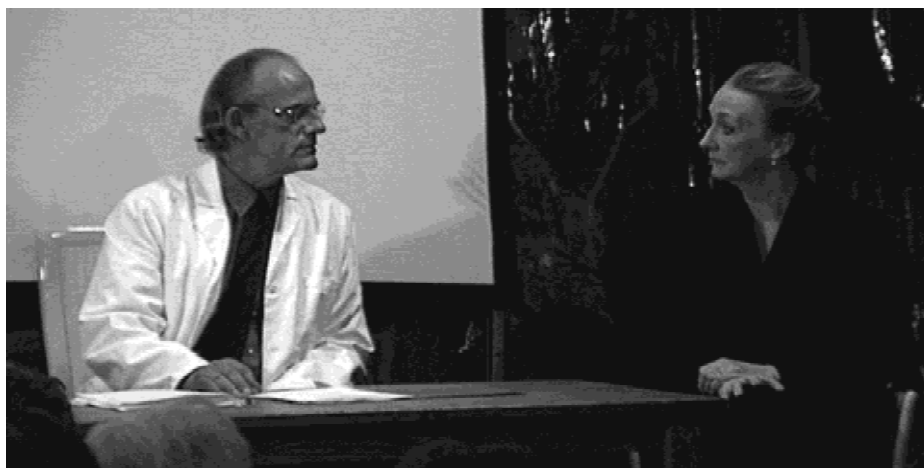
Each day, cancer is diagnosed in about 2,000 people in the United States. These patients need help and support in negotiating the many challenges that this illness presents. Hospital social workers and case managers often are too overworked to provide the support and personalized help that is needed. As a result, a new kind of profession has emerged—cancer patient advocacy. An unpublished feasibility study by The Porrath Foundation suggests that many cancer patients need, want, and will pay for the services of a professionally trained cancer patient advocate to help them negotiate the cancer process. Primary care physicians are ideally placed to take on this role.

PRIMARY CARE PHYSICIANS AS ADVOCATES

Once a diagnosis of cancer is made, patients are often inundated with an avalanche of in-

Ways in which the primary care physician can act as professional cancer patient advocate

- Understanding the diagnosis
- Informing family and friends
- Noting how illness might affect family, lifestyle, and work decisions
- Researching and choosing a medical team
- Arranging or attending meetings with cancer specialists
- Helping to determine treatment
- Understanding and managing treatment options
- Getting strategically prepared for new treatments on the horizon
- Gathering a complementary medicine team to provide mind/body support while undergoing traditional treatment
- During remission, determining and monitoring ongoing maintenance treatment and necessary checkups
- Helping with rehabilitation
- Being alert to recurrence
- Providing palliative care (referral to hospice and end of life care)
- Referring patients to resources that can help with insurance
- Referring patients to resources that can help with finances
- Cutting through hospital red tape
- Referrals for legal advice
- Offering support or referral to psychological services
- Helping patients to negotiate work and business affairs
- Helping patients arrange daily household maintenance and transportation regimen



Kevin Nicholson/EMJ

The physician who becomes a cancer patient advocate can be an informed, compassionate resource

formation and options. The professional cancer patient advocate can play the role of an informed partner and compassionate coach, helping patients to become active participants in their treatment and to recover a life that they may feel is out of control.

Primary care physicians, who often are more removed from cancer care institutions or health systems than are specialists, are freely able to help patients and caregivers navigate the treatment process and challenge the system when necessary. In the role of the professional cancer patient advocate, the primary care practitioner can provide invaluable support in numerous ways (see box).

The customary role of the primary care physician is to refer a patient with a diagnosis

of cancer to an oncologist. Frequently, once the oncologist moves into place and starts the process of working up and staging the disease, the primary care physician steps back and a cadre of cancer specialists takes over. Communication between the oncologists and primary care practitioner often becomes distant and infrequent; sometimes, it breaks down entirely. Some patients, depending on the course of their disease, do not return to the primary care provider but receive their care from the oncologists or their surgeon. If patients do return to see their primary care physician, it is only for routine health care because the oncologists direct their cancer care. In either case, the primary care physician is no longer the primary coordinator of care.

Cancer patients are often confused by this change and wonder why their own “regular doctor” is not more active in their treatment and disease management.

The primary care physician is well suited to step beyond the usual role as a referring physician to become a professional cancer patient advocate to stay involved in the care of their patient. The advocate can also be a resource for the many lifestyle, family, and quality-of-life decisions that must be made. Physicians can acquire additional continuing education training in the skills necessary to step into the process as mediator, negotiator, coach, counselor, and triage agent (see resources box).

Resources on cancer patient advocacy

- For information regarding a continuing education certificate program to become a Professional Cancer Patient Advocate, contact Jill Bauman, Interim Executive Director, Porroth Foundation for Patient Advocacy at pfpa@pacbell.net or visit www.cancerpatientadvocates.org.
- Center for Patient Advocacy, 1350 Beverly Rd, Ste 108, McLean, VA 22101; (703) 748-0400, 1-(800)-846-7444; advocate@patientadvocacy.org; www.patientadvocacy.org.
- Society for Healthcare Consumer Advocacy, (312) 422-3726; www.shca-aha.org.

A patient that changed my practice

The patient might be right

Callow and naive, I had recently started in family practice. But, full of confidence and believing I knew it all, I worked my way through my newly inherited list of patients with the enthusiasm that some of us may remember from earlier days. The Wing Commander stopped me in full flow: “I have come for my annual medical.” My protestations about the lack of evidence of benefit in such procedures were to no avail. His service background and a certain familiarity with health procedures in the United States gave support to what he thought was an entirely reasonable request. He was asymptomatic, with a clean medical history, and not taking any medication. He made his request simply and politely, and I had little option but to acquiesce.

I decided that, rather than just a simple blood pressure measurement and feel of his pulse I would “give him the works.” That should dampen his enthusiasm. Stripped and ready for examination, he chatted amiably as I set about checking him from top to toe. Cardiovascular system, normal; respiratory system, normal; cranial nerves, no appreciable disease; peripheral nervous system and musculoskeletal systems likewise. When I came across a mass just palpable in the left renal area, however, my indifference vanished rapidly. Early referral and surgery led to removal of a malignant, but fortunately entirely localized, tumor. His gratitude embarrassed me, since it was I who should have been grateful to him for teaching me, early in my career, that it is just possible that the patient might be right.

I went to see him last week. He is now 92 and has just had to give up his beloved fishing. I wanted to ask his permission to write about him. This was freely given, and we reminisced over our first meeting and what each of us has been doing over the intervening 30 years. And he has never once said, “I told you so.”

Peter Strangeways

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